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Retention of Study Partners in Longitudinal Studies of Alzheimer Disease

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Abstract

Background: Study partners are required for all participants at Alzheimer Disease Research Centers (ADRCs). Study partners' attitudes and beliefs may contribute to missed visits and negatively impact retention of participants in longitudinal AD studies.

Objective: Study partners (N=212) of participants (Clinical Dementia Rating [CDR]≤1) at four ADRCs were randomly surveyed to examine their facilitators and barriers to continued participation in AD studies.

Methods: Reasons for participation were analyzed with factor analysis and regression analysis. Effects of complaints and goal fulfillment on attendance were estimated with fractional logistic models. Open-ended responses were characterized with a Latent Dirichlet Allocation topic model.

Results: Study partners participated for personal benefit and altruism. Among participants with CDR>0, spouses were more likely to participate for personal benefit. Adult children were more

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Conflict of interest

The authors have no conflict of interest to report.

likely to participate for personal benefit when the participant was cognitively normal (CDR=0). Majority of study partners rated their ADRC participation as positive and meeting their goals. Although half reported at least one complaint, very few regretted participating. Those who reported that ADRC participation fulfilled their goals or had fewer complaints were more likely to have perfect attendance. Study partners requested more feedback about test results and better management of study visits.

Conclusion: Study partners are motivated by both personal and altruistic goals. The salience of each goal depends on study partner type and the participant's cognitive status. Fulfilling these goals may improve retention and reduce study partner complaints. Potential areas for improving retention are providing more information about the participant's test results and improved management of study visits.

Keywords

Alzheimer disease; facilitators; barriers; spouse; adult children

INTRODUCTION

Alzheimer disease (AD) is a progressive neurodegenerative disease that affects cognition and daily function. Given this, and that patients frequently lack insight into their impairment, all participants in AD clinical trials are required to enroll with a study partner. Study partners are family members or close friends who can provide valuable information about the cognitive, functional, and behavioral status of the participant over time [1–6]. They are often involved in a participant's decision to enroll in AD trials and to attend study visits [6–11]. Study partners accompany participants to study visits, ensure compliance with study protocols, and report adverse effects experienced by the participant [3, 6, 8, 10]. Retention, or consistent completion of study visits by participants and study partners, is critical to the success of longitudinal AD studies. However, research about study partners' facilitators and barriers to continued participation and their impact on retention in longitudinal AD studies is limited [7].

Similar to participants in longitudinal AD studies, study partners participate in hopes of medical benefit, access to experts and new treatments, altruism, and to contribute to AD research [7, 9, 12, 13]. In addition, barriers to participation, more generally, include informed consent, comorbidities, medications, risk/fear of side effects, barriers with procedures, medical burden, travel, and length and/or frequency of study visits [2, 14]. Study partners' facilitators and barriers to participation may vary by study partner type. Most study partners are spouses [9, 15, 16]. Compared to spouses, adult children may perceive greater health risks, such as side effects, from study procedures (e.g., annual assessments of clinical and neuropsychological function, magnetic resonance imaging, positron emission tomography imaging, lumbar punctures) and worse quality of life for their participant [15, 16]. Adult children may be less available to attend study visits than spouses, especially if they are employed or raising children [3, 9]. Spouses are more willing to participate in AD clinical trials [1, 15]. Limited evidence suggests that having a non-spouse study partner [3, 15, 17] or an unreliable study partner increases a participant's risk of dropping out [18]. Research regarding study partner age and subsequent risk of dropout is mixed [3, 15].

Therefore, we administered a survey to 212 study partners and 443 participants at four Alzheimer Disease Research Centers (ADRCs) to identify perceived facilitators and barriers to ongoing research participation. Evidence of participants' motivations for participation, concerns, goals, and desired enhancements and their impact on retention were published previously [13]. Additional research is needed to examine study partners' attitudes and beliefs, because they may contribute to missed visits, changing study partners, or even impact retention of participants in longitudinal AD studies. The purpose of this study was to examine study partners' facilitators and barriers in longitudinal AD studies. Collectively, insights into participants' and study partners' participation could influence the development and success of retention strategies to support study partners and participants in longitudinal AD studies.

MATERIALS AND METHODS

Participants

Study partners and participants in this mixed methods study were recruited from four ADRCs funded by the National Institute on Aging (NIA): Knight ADRC at Washington University in St. Louis, University of Pittsburgh ADRC, University of Wisconsin ADRC, and University of California, Irvine ADRC. Study partners and participants were eligible if the participant: (1) was 45 years of age or older, (2) was currently enrolled in longitudinal studies, and (3) had a global Clinical Dementia Rating® (CDR) [21] score of ≤1 at their most recent clinical assessment. Study partners were not eligible if their participant was institutionalized and/or did not live in the geographic region of the ADRC.

Eligible study partners and separate participants were randomly selected and invited to participate between their annual ADRC visits. Prior to all study procedures, study partners and participants provided written informed consent if consented in person or verbal consent if recruited via phone. These procedures were approved by the Institutional Review Boards at all four ADRCs.

Study Procedures

Study partners and participants completed a 20-minute survey about facilitators and barriers to retention in longitudinal studies in person using an iPad during a break at their annual ADRC visit, or via telephone with a trained rater. All data were collected using Research Electronic Data Capture (REDCap) [22]. Study partners and participants received a $5 gift card for participating. The National Alzheimer's Coordinating Center Uniform Data Set was used to analyze demographic information for these study partners [23, 24].

Measures

We created a 57-item assessment, including the participant and study partner versions of the Perceived Research Burden Assessment [25] and two open-ended questions to assess study partners' and participants' perceived facilitators and barriers to continued participation in longitudinal AD studies. Items from the survey were ranked using a Likert scale from 1 (strongly disagree) to 5 (strongly agree), unless otherwise noted. The final survey is

included in the Appendix. Additional information about the development of the assessment is published elsewhere [13].

We also examined how study partners' perceived fulfillment of their goals and their complaints about study participation affected their attendance rates. Attendance rates were the percentage of visits that the study partner attended divided by the total number of expected visits at the ADRC.

Statistical Analyses

Data were entered directly into REDCap [22], a secure, web-based application with real-time validation. We used quality control programs to verify identification, evaluate consistency, and monitor recruitment and retention throughout the study. We computed response frequencies for all items and transcribed and thematically coded open-ended responses. Data analyses were conducted in STATA 15.1 (StataCorp, LLC, College Station, TX).

We performed principal component factor analysis to estimate and explain the latent structure of reasons for participation. We also used regression scoring to generate factor scores rotated with varimax (orthogonal) and promax (oblique) techniques. Linear regression analysis of the factor scores was by ordinary least squares with robust (Huber/White/sandwich) standard errors. The ordinary least squares models included interaction terms between cognitive impairment of the participant (CDR>0) and the study partner's relationship to the participant. This allowed us to estimate the marginal effect of cognitive impairment for different types of study partners. Attendance rates were analyzed with the procedure "fracreg" (fractional logistic regression). The topic models were estimated with "ldagibbs," a Latent Dirichlet Allocation machine learning topic model. The analysis included controls for the ADRC site of the study partner.

RESULTS

Across the four ADRCs, 212 study partners completed the survey. Demographic characteristics for study partners by study partner type and overall are included in Table 1. The relationships of study partners to participants were 64% spouses, 17% adult children, 11% siblings or other relatives, and 8% other (non-familial) relationship, such as a friend or neighbor. Results from the 443 participants were published previously [13].

Goals of Participation and Perceived Satisfaction

Study partners' general assessment of their participation was highly positive. Nearly all (>95%) agreed or strongly agreed that their participation was valuable and that they were accomplishing their goals for participation. A small share of study partners (<6%) agreed or strongly agreed that they regretted their decision to participate or that they had second thoughts about participation.

Perceived Facilitators

Most study partners strongly agreed that their reason for supporting their partner's participation was to advance AD research (85%) and to benefit society and future generations (80%; Figure 1). The principal factor analysis of the reasons for supporting their partner's participation identified two orthogonal dimensions: reasons involving personal benefits for the participant and reasons involving altruism (Table 2). The eigenvalues for the first three factors (2.71, 1.47, and 0.52) strongly supported a two-factor model. An oblique rotation revealed a weak (0.22) positive correlation between the dimensions, supporting an orthogonal model.

Study partners varied in whether they emphasized personal benefits as a function of their relationship to the study participant and the CDR score of the participant. When the participants had a CDR>0, spouse study partners ($p<.01$) and sibling study partners ($p<.01$) were more likely to emphasize personal benefits than were children of participants ($p<.01$). But when the study participant was cognitively normal (CDR=0), study partners who were adult children emphasized personal benefits more than spouses ($p<.01$). But turning to altruistic goals, study partners' emphasis increased with their level of trust in medical researchers.

Perceived Barriers

Overall, about half of study partners (51%) endorsed at least one of the 19 possible types of complaints offered on the survey. Complaints with which at least 5% of study partners agreed or strongly agreed were: fatigue (15.2%), inconvenient travel (13.0%), distance (12.3%), physical pain (11.9%), breach of privacy (9.4%), visits too long (9.0%), emotional distress (8.1%), and difficulty keeping track of procedures (6.3%). Frequencies and types of complaint were generally consistent across age cohorts, sex, and race.

Effects of Perceived Fulfillment of One's Own Goals and Complaints on Retention

For 207 of the 212 study partners surveyed, information was available about the number of possible (scheduled) study visits and the number of completed study visits as of January 25, 2021. The number of expected visits ranged from 0–23. Overall, the attendance rate was high. For participants with at least two possible study visits (N=184), 71% had perfect attendance, and the average attendance rate was 93% (SD=16%).

Table 3 reports fractional logistic regression results estimating the effects of study partners' perceived fulfillment of their goals and perceived complaints on their attendance rates. The analysis of attendance rates included only study partners with two or more possible visits and included a control variable for the total number of possible visits. The control variable ensured that the number of possible visits would not confound the analysis because, for example, the study partners most committed to the study may have both relatively high attendance rates and relatively long histories of visits.

Study partners who reported that ADRC study participation fulfilled their goals for their partner had, on average, higher odds of having perfect attendance (OR=1.44, 95% CI: 1.01–2.06). Study partners with a higher number of complaints had lower odds of perfect

attendance (OR=0.83, 95% CI: 0.70–0.99). None of the most common complaints (Figure 2), on their own, achieved a statistically significant association with rate of attendance.

We observed no consistent independent effects on attendance of age, gender, or self-reported race. Study partners who were children of a participant had higher attendance than those who were spouses (the baseline category in the statistical models).

Open-ended Comments about Improving Participant Study Experience

The survey included an open-ended question, “What is the most important thing that ADRC researchers could do to enhance your and your [study partner relationship] experience with the study?” One hundred ninety-three study partners responded with a comment. These were typically brief, but some study partners offered several sentences. Figure 2 presents the results of a topic model summarizing these comments. The model excluded words with fewer than five letters and assumed comments focused on a small number of topics. We selected six topics based on model fit and the interpretability/coherence of the topics.

Many comments were positive and offered no criticism or suggestions. The largest topic, “satisfied with study,” captured these and accounted for 31% of all comments. Study partners’ suggestions and concerns fell into five categories. The largest of these topics (20%) included requests to provide more feedback about participants’ test results and performance at study visits. Study partners also raised concerns about the management of their study visits (14%) and study participation generally (13%). Finally, study partners sought more information about AD and related research findings (11%) and about their participant’s progression to AD (10%).

DISCUSSION

We examined study partners’ facilitators and barriers to participation at four NIA-funded ADRCs [13]. Study partners influence participants’ enrollment in and attendance of study visits [6–11]. Strategies are needed to retain both participants and study partners and reduce missed visits. Our results with study partners are consistent with our previous research with participants [13] in multiple ways: (1) the structure of reasons for participation for study partners and participants, including personal benefit and altruism, which are related to trust in medical researchers and the participant’s CDR score; (2) the relationship between perceived fulfillment of one’s own goals and higher attendance; and (3) the primary topics of open-ended responses about enhancing the study experience.

These similarities indicate that a similar set of retention strategies may be valuable for retaining study partners and participants. For example, personal benefits weigh more heavily than altruistic motivations for participants who have CDR>0 and for most study partners (i.e., who are spouses). Retention strategies targeted at enhancing perceived personal benefits, such as providing more feedback on tests, could increase retention of participants and most study partners. However, the one place where we did not see alignment in goals was with study partners who are adult children, whose emphasis on personal benefit tended to move opposite that of participants at CDR>0. This calls for a more nuanced approach

to retention to address the differential emphasis on personal and altruistic goals between participants and study partners.

Regarding reasons for participation, personal benefit was emphasized by different types of study partners based on whether their participant suffered from cognitive impairment. Adult children endorsed personal benefit when their participant had no cognitive impairment (CDR=0). Compared to adult children, spouses and siblings were more likely to emphasize personal benefit when the participant had cognitive impairment (CDR>0). Spouses may seek resources to address their participant's memory concerns, access to medical centers, and access to future treatments when their participant is impaired. Conversely, adult children may participate more for altruistic reasons when their participant has cognitive impairment (CDR>0), such as to advance AD research and benefit future generations of their family. Altruism was emphasized by study partners with more trust in medical researchers. Perceived facilitators to study partner participation included advancing AD research and benefits to society and future generations. Similar to previous research, the number of perceived barriers to participation endorsed by study partners was limited and included fatigue, inconvenient travel, distance, physical pain, breach of privacy, long visits, emotional distress, and difficulty keeping track of procedures [2, 14].

Our results indicate that study partners whose goals were met or who had fewer complaints were more likely to attend more ADRC visits than those whose goals or complaints were not met/addressed. This has direct implications for missed visits in longitudinal AD studies. We found that adult children had higher attendance rates than spouses, which runs counter to the limited evidence that having a non-spouse study partner increases a participant's risk of dropping out [3, 15, 17, 18]. As such, it is imperative to identify study partners' goals in conjunction with barriers to participation over time and utilize different strategies for adult children and spouses to positively impact retention [15]. For example, for spouses and siblings of participants with cognitive impairment (CDR>0), strategies that emphasize addressing concerns about memory and access to expertise, resources, and future treatments may positively impact attendance. Study partners with higher trust in researchers may respond better to strategies that appeal to their altruistic goals for participation, such as to advance AD research and to benefit society and efforts to share these advances with them.

Study partners' open-ended responses provided additional opportunities to indicate factors in their participation in longitudinal AD study procedures. Although the majority of comments were positive, study partners' complaints included management of their study visits and study participation generally. Strategies to address these concerns may vary based on type of study partner. For example, adult children, who may be employed and raising their own families, may benefit from additional communication regarding study visits and procedures so they can plan accordingly [3, 9]. Additional suggestions from study partners included more feedback about participants' test results/performance [26] and progression to AD as well as more information about AD and research findings, which align with participants' suggestions [13]. ADRCs could provide updates about the participant's functional changes over time, include more education about early signs of AD, or share more updates about research findings with participants and study partners via existing newsletters or events.

Although the results are informative, this study has limitations. Similar to our previously published findings with participants [13], study partners who participated in this study may have been more committed than study partners who dropped out. We do not know whether the facilitators and barriers identified for the enrolled study partners differed from those of individuals who stopped attending, because Institutional Review Boards have restrictions about contacting individuals who drop out. In addition, while adult children attended more visits than spouses, they made up a small proportion of study partners in this study. The ADRCs engaged in this study collect limited information about the characteristics of study partners. Thus, we do not know whether the adult children in this study were employed, had children of their own, or lived with the participant, which would have helped us to better understand our results and their impact on participation overall. The majority of study partners were White and non-Hispanic, which also affects the generalizability of our findings. Last, this study only included study partners at four ADRCs, which may not be generalizable to other ADRCs or to other, non-observational types of AD research, including clinical trials.

Regardless, it is essential to examine study partners' and participants' facilitators and barriers to participation over time, especially if the participant's cognitive status changes. These findings could be used to develop comprehensive strategies to meet the needs of adult children and spouse study partners as they age and manage their own health and families and their participants. Providing study partners with test results [26] or AD research updates could enable them to plan for the future. It also could increase their feelings of fulfillment, particularly for their goals involving personal benefit, and thereby positively impact retention for both study partners and participants in longitudinal AD studies.

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Data Availability

The data supporting the findings of this study are available on request from the corresponding author.

APPENDIX

Appendix

Appendix. Sample Study Partner Survey

NACC Collateral Source Survey

This survey will ask you about your experiences as a study partner in Alzheimer disease research at _____. There are no right or wrong answers for the following survey questions; we simply wish to know your thoughts and opinions. Your responses will remain anonymous, and the researchers who conduct your annual visits will not know who participated.

First, I would like to ask:	
Do you personally know or have you known someone with Alzheimer disease?	Yes no
Next, I am going to ask some questions about your reasons or motivations for supporting your family member or friend's participation in the study. I am going to read a statement and I would like you to respond with the answer that best reflects your opinion. The answer choices are: strongly agree, agree, neutral, disagree, and strongly disagree.	
I support my family member or friend's participation in the study to advance research about Alzheimer disease.	Strongly agree, Agree, Neutral, Disagree, Strongly disagree
I support my family member or friend's participation in the study to benefit society.	Strongly agree, Agree, Neutral, Disagree, Strongly disagree
I support my family member or friend's participation in the study to benefit future generations of my family.	Strongly agree, Agree, Neutral, Disagree, Strongly disagree
I support my family member or friend's participation in the study because I have concerns about their memory.	Strongly agree, Agree, Neutral, Disagree, Strongly disagree
I support my family member or friend's participation in the study to gain access to support at the medical center (advice and expertise).	Strongly agree, Agree, Neutral, Disagree, Strongly disagree
I support my family member or friend's participation in the study to learn more about Alzheimer disease and other dementias.	Strongly agree, Agree, Neutral, Disagree, Strongly disagree
I support my family member or friend's participation in the study to have access to future state-of-the-art treatment and information.	Strongly agree, Agree, Neutral, Disagree, Strongly disagree
I support my family member or friend's participation in the study because they enjoy spending time with the staff.	Strongly agree, Agree, Neutral, Disagree, Strongly disagree
Next, I'd like to ask about your thoughts on your family member or friend's participation in our study. I am going to read a statement, and I would like you to respond with the answer that best reflects your opinion. The answer choices are: strongly disagree, disagree, neutral, agree, or strongly agree.	
I feel that study visits are too frequent.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I feel that study visits are too long.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree

I feel that study visits take away from time with my friends and family.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I feel that researchers ask me too many questions.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I feel that researchers ask my family member or friend too many questions.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I feel that researchers ask me questions that are too personal.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I feel that researchers ask my family member or friend questions that are too personal.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I feel that researchers call or contact me or my family members too often.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I worry that my personal information might not be kept private.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I feel that the research site is too far away.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I feel that it is inconvenient to get to the research center.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I feel that it is inconvenient to park at the research center.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I feel that my family member or friend became emotionally upset by the MAP study procedures (If so, which one or all_____)	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I worry that my family member or friend may be physically harmed by some of the research procedures.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I feel that I had to persuade or coax my family member or friend to come to the research center.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I feel that I had to persuade or coax my family member or friend to cooperate with certain aspects of the research study.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I have had second thoughts about my decision to participate in the study.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I regret my decision to participate in the study.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I feel that this study takes too much time away from my chores and household responsibilities.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I feel that this study takes too much time away from my job.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I feel that it costs too much to transport my family member or friend to the research center.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
My family member or friend became fatigued from the research procedures.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
My family member or friend experienced side effects from the research procedures.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree

My family member or friend experienced physical pain or discomfort while participating in this study.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I feel that my family member or friend's health got worse while I participated in this study.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
It is hard for me to accompany my family member or friend to their study interview.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I feel that study visits have negatively affected my relationship with my family member or friend.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I find it difficult to keep track of the different procedures in the study.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I believe my research participation is valuable.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I understand why my friend or family member is asked to participate in so many different procedures.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
I am accomplishing my goals for participating in the study.	Strongly disagree, Disagree, Neutral, Agree, Strongly Agree
The next set of questions asks about specific visits for this study. I am going to read a statement, and I would like you to respond with the answer that best reflects your opinion. The choices are: very positive, positive, neutral, negative, or very negative.	
My family member or friend's last clinical assessment interview visit was:	Very positive, Positive, Neutral, Negative, Very negative
My family member or friend's last memory testing visit (neuropsychological examination) was:	Very positive, Positive, Neutral, Negative, Very negative
My experience with my family member or friend's last lumbar puncture visit was:	Very positive, Positive, Neutral, Negative, Very negative
My experience with my family member or friend's last imaging visit was:	Very positive, Positive, Neutral, Negative, Very negative
Now I'd like to ask about any additional studies you might be involved in.	
In addition to clinical core visits, have you been invited to participate in additional research studies at the Knight Alzheimer Disease Research Center (for example, driving studies; sleep studies?)	Yes no; If yes, how many
Have you participated in any of the additional studies?	Yes no; If yes, how many
Do you participate in research studies not related to the Knight Alzheimer Disease Research Center?	Yes no; If yes, how many
Next, I have a few questions about your views on medical researchers. I am going to ask a question, and I would like you to respond with the answer that best reflects your opinion. The answer choices for this question are: not at all, a little, some, quite a bit, or a great deal.	
All things considered, how much do you trust medical researchers?	Not at all, A little, Some, Quite a bit, A great deal
For the next two questions, the answer choices are: never, rarely, sometimes, very often, and extremely often.	

When they are conducting research, how often do medical researchers have the best interests of participants from your racial or ethnic group in mind?	Never, Rarely, Sometimes, Very often, Extremely often
How often do medical researchers tell participants everything they need to know about the risks of participating in their studies?	Never, Rarely, Sometimes, Very often, Extremely often
For the next three questions, the answer choices are: strongly disagree, disagree, neutral, agree, and strongly agree.	
I have a positive view about medical research in general.	Strongly disagree, Disagree, Neutral, Agree, Strongly agree
We all have some responsibility to help others by volunteering for medical research.	Strongly disagree, Disagree, Neutral, Agree, Strongly agree
Society needs to devote more resources to medical research.	Strongly disagree, Disagree, Neutral, Agree, Strongly agree

I have two last questions for you. These questions don't have answer choices.

1. What is the most important thing that our researchers could or already do to enhance you and your family member or friend's experience with the study?

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2. Do you have anything else you would like to share about your experience as a study partner?

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Interviewer notes:

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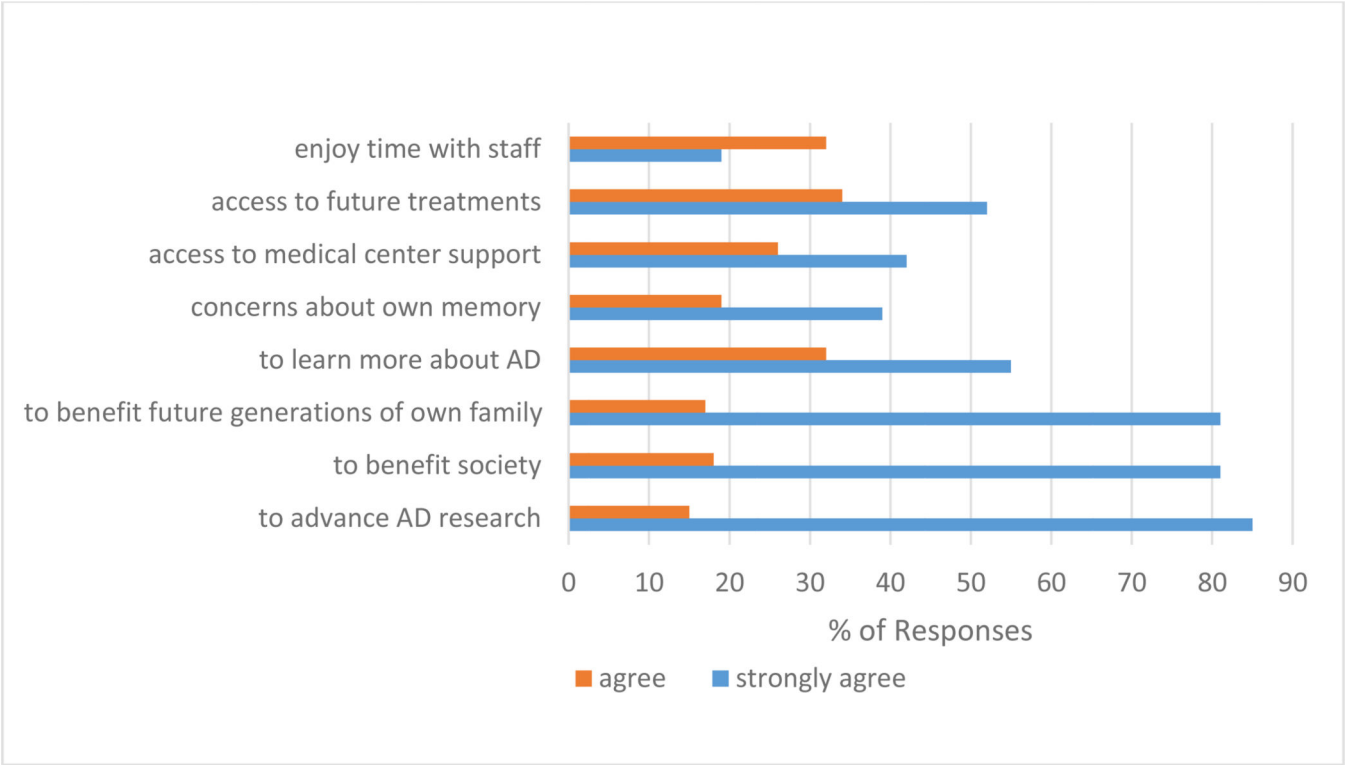

Figure 1.
Reasons for Participation in ADRC

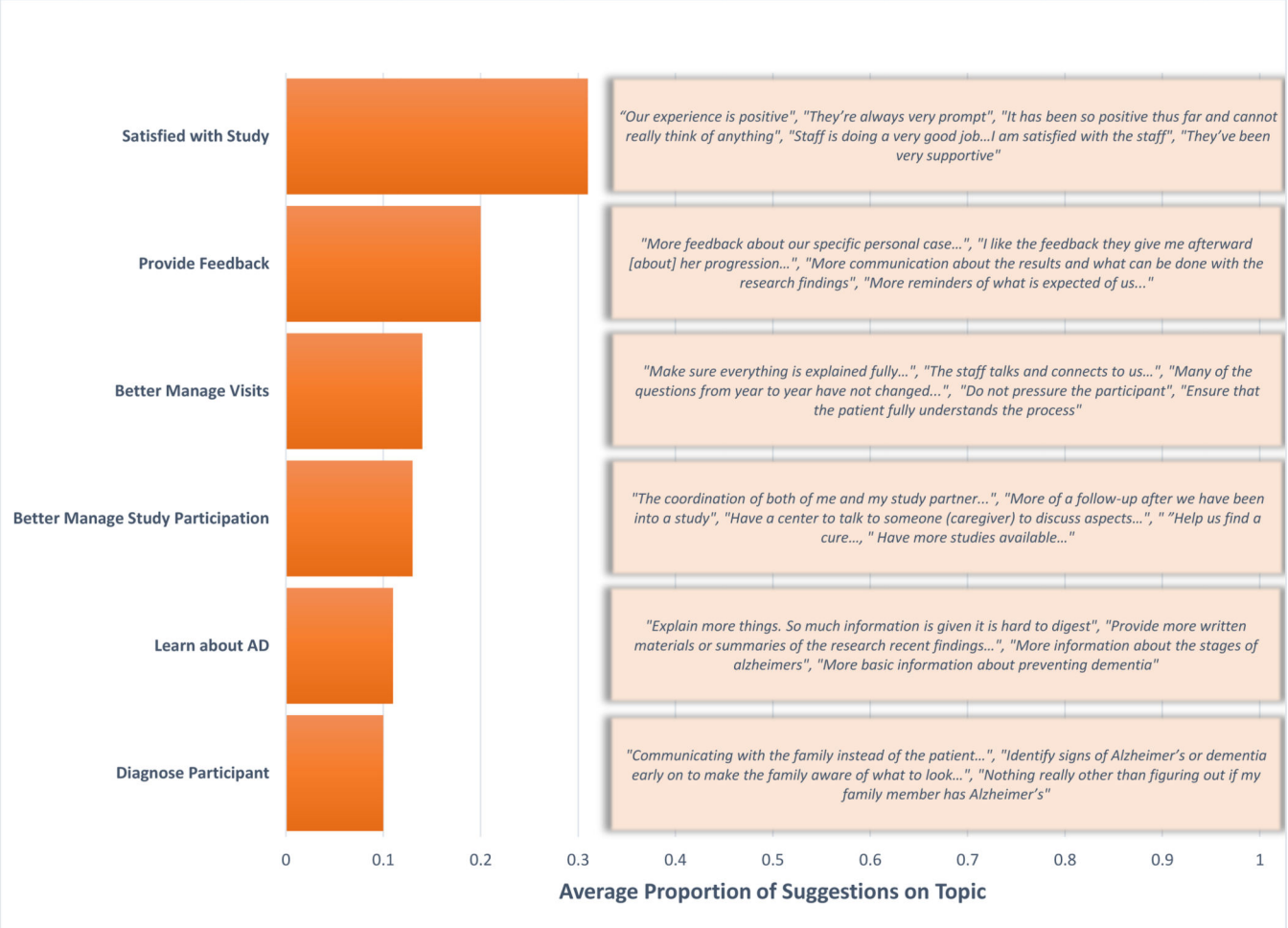

Figure 2.
Topic Model of Study Partners' Suggestions to Enhance their Study Experience

Table 1.

Demographic characteristics of study partners by study partner type and overall

	Study Partner Type*			
	Spouse (n=136)	**Adult Children (n=35)**	**Other (n=39)**	**Total (n=210)**
Age, Mean (SD)	71.5 (8.7)	50.4 (8.8)	70.9 (5.5)	67.4 (12.0)
Missing, n (%)	20 (15%)	1 (3%)	7 (18%)	28 (13%)
Gender, n (%)				
Female	76 (56%)	26 (74%)	33 (85%)	135 (64%)
Male	60 (44%)	9 (26%)	6 (15%)	75 (36%)
Race/Ethnicity, n (%)				
African American	10 (7%)	3 (8%)	5 (13%)	18 (9%)
Asian	9 (6%)	1 (3%)	2 (5%)	12 (6%)
White	95 (70%)	28 (80%)	24 (62%)	147 (70%)
Other	1 (1%)	1 (3%)	0 (0%)	2 (1%)
More than one race	1 (1%)	0 (0%)	0 (0%)	1 (0%)
Missing	20 (15%)	2 (6%)	8 (20%)	30 (14%)
Hispanic, n (%)				
Yes	3 (2%)	0 (0%)	0 (0%)	3 (1%)
No	114 (84%)	34 (97%)	32 (82%)	180 (86%)
Missing	19 (14%)	1 (3%)	7 (18%)	27 (13%)
Years of Education, Mean (SD)	16.0 (3.0)	19.1 (14.5)	15.2 (2.8)	16.5 (6.9)
Missing, n (%)	23 (17%)	2 (6%)	9 (23%)	34 (16%)
Clinical Dementia Rating (CDR) of participant, n (%)				
CDR=0	56 (41%)	3 (9%)	20 (51%)	79 (38%)
CDR>0	47 (35%)	15 (43%)	12 (31%)	74 (35%)
Missing	33 (24%)	17 (48%)	7 (18%)	57 (27%)

*Study partner type was missing for two study partners, so they are not included in this table.

Table 2.

Factor[†] and Regression Analyses of Reasons for Participation

Reasons for participating	Factor 1 (Personal benefit)	Factor 2 (Altruism)
To advance AD research	0.02	0.81
To benefit society	0.08	0.79
To benefit future generations of own family	0.21	0.66
Because I have concerns about memory	0.63	−0.03
To gain access to future treatments	0.79	0.18
To learn more about AD	0.69	0.25
To enjoy time with staff	0.38	0.14
To access medical center support	0.82	−0.02
Predictors of the factor scores for each category of motivation (OLS regression coefficients and robust standard errors)		
CDR Score>0 (0 if CDR=0; 1 if CDR>0)	1.07** (0.16)	−0.04 (0.17)
Child	0.73** (0.27)	−0.13 (0.70)
Child*CDR Score>0	−0.92** (0.31)	0.28 (0.70)
Sibling	0.11 (0.31)	0.02 (0.72)
Sibling*CDR Score>0	0.14 (0.35)	−0.28 (0.45)
Other relationship	0.24 (0.50)	−0.20 (0.37)
Other relationship*CDR>0	−0.22 (0.51)	0.21 (0.48)
Trust medical researchers (1, not at all, to 5, a great deal)	−0.09 (0.07)	0.27** (0.10)
Male	−0.08 (0.17)	−0.07 (0.18)
Black	0.08 (0.22)	−0.06 (0.20)
Asian	0.30 (0.31)	−0.47 (0.42)
Other race	0.56 (0.33)	−0.26 (0.55)
N	208	208
Adjusted R^2	0.31	0.11

AD, Alzheimer disease; OLS, ordinary least squares; CDR, Clinical Dementia Rating.

[†]Varimax (orthogonal) rotation. The baseline survey respondent was a White female spouse of a study participant with CDR=0. All models included controls for ADRC site.

** p<.01

* p<.05.

Table 3.

Perceived Efficacy, Barriers, and Participation

	Attendance rate		
Accomplishing goals (range: 1–5)	0.36* (0.18)	—	—
Number of complaints (range: 0–19)	—	−0.18* (0.09)	—
Fatigue	—	—	0.29 (0.18)
Inconvenient travel	—	—	−0.17 (0.33)
Distance	—	—	0.45 (0.34)
Physical pain	—	—	−0.00 (0.21)
Breach of privacy	—	—	−0.18 (0.23)
Visits too long	—	—	−0.05 (0.27)
Emotional distress	—	—	−0.06 (0.21)
Difficulty keeping track of procedures	—	—	0.12 (0.22)
Sibling	−0.59 (0.41)	−0.65 (0.23)	−0.53 (0.51)
Child	1.29* (0.61)	1.38* (0.56)	1.63* (0.83)
Other relationship	0.24 (0.64)	0.17 (0.68)	0.12 (0.65)
Male	0.37 (0.42)	0.42 (0.47)	0.28 (0.50)
Black	−0.60* (0.49)	−0.74 (0.54)	−1.04 (0.55)
Asian	−2.17 (1.19)	−2.08 (1.09)	−2.15 (1.21)
Other race	−0.23* (0.92)	−0.20 (0.96)	−0.53 (0.93)
Age	0.06* (0.02)	0.07** (0.02)	0.07* (0.03)
Total possible study visits	−0.10** (0.03)	−0.10** (0.03)	−0.10* (0.04)
N	153	158	151

This table presents fractional logistic regression results for attendance rate, excluding participants with fewer than two possible visits. Log odds ratios are reported with standard errors in parentheses. All models include controls for ADRC site.

* $p<0.05$.